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**“Where’s beebee?”:
The orphan crisis in global child welfare from an
autoethnographic perspective**

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“Where’s beebee?”:

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Abstract

“Where’s beebee” asked our year-old son David in the only way he could, which was by carrying around a toddler-sized doll everywhere he went, often saying, “beebee?” This was his way of saying that he was missing his twin brother, who was separated from him by several tragic circumstances in the international adoption process. Combining personal narrative with a comprehensive literature review, this autoethnography chronicles my journey to parenthood through the international adoption process, which became an introduction to Guatemala and the Mayan people, the dark side and angels of human nature, experiences with parenting a disabled child, and the miracle of the infant brothers’ love for each other. Autoethnography is a critically important methodological tool here because the facts told in this story cannot be otherwise known: The international orphan crisis is characterized by the problem that the infants and children who are the basis of the crisis disappear due to horrors including kidnapping, abuse, slavery, chronic malnutrition, disease, orphanage neglect, and genocide. This is fundamentally a love story, but also I hope you find this story enlightening about the importance of corrective understandings and actions on behalf of those orphans who so profoundly need advocates.

Introduction

This is the story of my personal journey to parenthood, which due to accidents of timing and a fateful coincidence of local and global influences on Guatemalan adoption, quickly swept me into some of the most enshadowed and sinister corners of the orphan crisis in global child welfare. It also led to a story of love between two infant boys that is remarkable and inspiring. The story told here has many ways of telling: one for my little sons on their third birthday, another when they are 12; one for their doctors and helpers, others for friends, one we sought to tell to an international human rights tribunal for redress. The telling for you here, striving to follow principles of autoethnography, is crafted to best make known what cannot be known if one is limited to scientific traditions and even the most flexible of multi-method social science studies.

This story cannot be otherwise known because the people who are the basis of the facts one could gather using other methods disappear. The infants disappear: kidnapped, sold to Fagins who will turn them into thieves and criminals, or they die slowly of malnutrition, illness, lack of love, grief... or they are disabled by criminal acts or deprivation of medical care readily available in industrialized nation and live lives of unimaginable pain in countries that have no resources to care for those who cannot fend for themselves in the most basic ways (Lykes 1994). The infants cannot speak and even if they could, who can gather those statistics and stories into a neatly bound research package? An IRB would shudder at the thought of what would be needed to cross national boundaries and take on such questions. Even more harrowing is that Guatemala is among the countries where researchers face profound opposition by those aspects of government seeking to hide their genocidal allegiances (Melville & Lykes, 1992). Human rights activists supporting indigenous peoples are frequently murdered in Guatemala (see Human Rights Watch, 2009). The story you will read happened and in that sense this story bears witness in a way that cannot be known through customary research methods.

So enough prelude... except for one set of thoughts about the inner place where the story begins. Parenthood starts with some dream, like a seed, born of ancient memories and personal experiences of caring and being cared for, and in this dream, every parent is looking, somehow and in however focused or fragmented a way, for a child. And in my parent dream I wondered who that child would be, imagined loving that child, discovering the wonderful person the child could become and hoping to be up to the job of helping the child become that wonderful person. Then as the dream comes to earth, one gradually knows that this dream will not just live in one's heart, but become one's very heartbeat; it is a dream of life but of life so deeply important it means more than one's own bones and breath: it means the ability to love, to live what life is meant to be, to join the core of the universe with one's tiny humble breath. Some paths to parenthood become more entangled and it feels as deeply threatening as tumbling into quicksand or an avalanche crashing; whether entangled or straight, parenthood can be lofty with fruitful meaning and permanent, like residing in the most beautiful place in the world doing the most fulfilling work possible with the best partners.

When into these dreams of parent love with their possible incarnations appear some of the world's over 100 million orphans (figures are controversial because some

define orphan as those without parents or family, such as estimates there are 25 million due to HIV-AIDS alone, per TvT Associates/The Synergy Project 2002; Roby & Shaw, 2006; others include in the definition of orphans those children whose birth families relinquish them, often due to poverty), the entangled or straight road to parenthood suddenly has other dimensions only glimpsed through a glass darkly even by those claiming to be experts. As a professor of social work going for help to adopt a child, I had read about difficulties and controversies in international (Knoll and Murphy 1994) and transracial adoption (Bartholet 1991; Bartholet 1993), but I could not foresee what a wild country the field of adoption can be from an adoptive parent's point of view.

If you decide to read this story, I hope our encounters with the dark and noble sides of human nature will underscore the importance of corrective understandings and actions. I hope you will experience the courage of two infant twins who dared to hold onto their love for each other despite disruptions by life-threatening illness, neglect, cruelty, and corruption. I hope you will know a bit more about what actually happens when mothers made desperate by poverty want to spare their newborns the threat of kidnapping, slow death from starvation, or the suffering of mortal illness and disability, and find the courage to give them over to strangers in the hope the children will find a better life.

Beginning

So it was with the birth mother who gave us our boys. During our cold, snow-laden winter in Chicago she traveled several times from her tropical Mayan city by the sea in Guatemala to the country's capital to register her healthy twin sons' birth, reveal her story to social workers and others seeking to verify the authenticity of her intentions and actions, even making a videotape for the lawyer to satisfy inquisitorial opponents of international adoption in Guatemala. For she had borne and given birth to healthy twin sons and it was worth all those steps and all that humiliation to try to give them, as she put it, a better life than what she could manage, abandoned as she was by the babies' father and her own family. We never could meet her but knew her through her documents: the phrases she gave the interviewers, her pictures. Her face looked terribly sad but also etched with determination, for she had to give up those babies right away to a foster mother, and yet see them several times again, attesting each time that she had not been coerced, bribed, or forced in any way to have the children or give them up for adoption. And she had to give up her blood so it could be matched with her baby twins' blood, to ensure the boys had not been kidnapped. Her mourning process held hostage by the levels of bureaucratic suspicion and drudgery, she nonetheless maintained in her expression a combination of hope and fierce dignity. And we are forever grateful to her for her choice and her courage in carrying it out.

Tragedies usually initiate any adoption story. Legitimate birth parents only relinquish their children because they are overwhelmed by tragic events such as poverty, shame if the child is conceived out-of-wedlock, horrible circumstances such as rape leading to the conception, or being so young as to be unable to care for a child. There are usually tragic reasons why adoptive parents do not conceive, and given corruption in both domestic and international adoption, adoptive parents are prey to being misled and virtually robbed by birth mothers and adoption agencies.

My husband Bob and I had an active domestic application pending but had already experienced one profound disappointment when the birth mother changed her mind. Like many parents aching from a lost domestic placement and wanting to make their dream come true, we looked at international adoption because while there were hurdles unique to international adoption, in 2006 it was also believed to be more straightforward: When you were given your child's dossier by an international adoption agency, the adoption moved forward. We looked hard for reputable agencies, which also clearly exist, run by people who actually fight to be able to save the lives of orphans by arranging adoptions, ironically despite considerable opposition and negative public opinion. We chose both China and Guatemala, each of which were sending about 4,000 babies to the United States for adoption every year, babies who were unwanted in their countries (China because of discrimination against women [Evans 2000; Johnson 2004], Guatemala because of the genocidal discrimination against the Maya). There were some very desirable features of adoption from Guatemala: the children were in foster care rather than orphanages as in China, and were usually adopted in the first 6 months, unlike a China adoptee who would be 12 months or older. So we filled out what seemed like an endless number of papers documenting that we are who we say we are, with all documents stamped by city, state, and federal authorities and, in the case of Guatemala, by the Guatemalan consulate. We had our fingerprints taken several times. We took classes on international and transracial adoption, read books, signed papers, sent money to guarantee our adoptee would be well cared for in every way, and were in line then for babies from the United States, China, and Guatemala.¹

History

When Bob and I started our journey to adopt in Guatemala, we knew some basic facts and we quickly learned more. Guatemala is a country trying courageously to implement a parliamentary democracy in the wake of centuries of colonialization by the Spanish, a long history with the slave trade, and decades of genocide against the Mayan people who are the majority of the population. The Mayan people in Guatemala suffered some of the worst, recent state-sponsored genocide in the world (Sanford 2003). Two researchers who interviewed 68 Mayan child refugees whose family members were

¹ We were both very aware of the opinion that international adoption is highly problematic because of imbalances in resources and power available to poorer countries (usually "sending" countries in international adoptions) and more wealthy countries (usually "receiving" countries). For us, the view that boundaries of nations take precedence as the major considerations in deciding the fates of children is a relic of the view that infants and children are not persons with their own autonomy and boundaries to be respected, but are instead first and foremost property (in this case, of their nations). In other words, from a perspective prioritizing the human rights of the individual child, the impact of the claim that infants and children are first and foremost property of their countries in effect subjects large numbers of infants and children to infanticidal sexism, genocidal racism, brutal neglect or maltreatment because of cultural values that relinquished children of unmarried persons or orphaned children have "bad blood," institutionalization that damages their brains (Nelson, Furtado, Fox & Zeanah, 2009), or lives of perpetual abuse on the brink of starvation as street children. In short, the country-prioritizing perspective is oppressive of infants, children, and youth, and adultcentric (Petr, 1982). By contrast, the opportunity to be adopted internationally offers infants, children, and youth the human right to live the best lives possible and develop their own freedom of choice about their familial, cultural, and national allegiances, and it offers many countries resources to develop a child welfare infrastructure that otherwise would not be available (we side completely with Elizabeth Bartholet's most articulate analysis, 2007, 2010).

murdered, 'disappeared,' or kidnapped summarized as follows:

The trauma experienced by the Mayan children in Guatemala resulted from hostile Guatemalan Army incursions into their villages, that involved the indiscriminate torture and physical elimination of individuals, families, and even of entire communities, and the forced relocation of many, especially during the years 1981-1983. The children also experienced random, forced disappearances of family members without respect to age or gender and the concomitant uncertainty of their fate, as well as witnessing horrible mutilations evident in the bodies purposefully left by the army to terrorize the population (Melville & Lykes, 1992, p. 533).

According to the Guatemalan Supreme Court of Justice, over 200,000 children lost one or both parents in the carnage; several hundred thousand families sought refuge in Mexico, Belize, and the United States (Melville & Lykes, 1992, p. 535). It is likely the birth and foster mothers of our children, who would have been children at the time, were exposed to the violence. Even in 1992, while the large-scale civil warfare had abated, continued terrorist acts against Mayan villagers by the Guatemalan army continued.

The reason for the many Mayan infants available for adoption became apparent as we continued our research. In 2007, one of the Presidential candidates included a Mayan activist and Nobel Peace Prize laureate (Rigoberta Menchu, [Menchu 1984]), running against candidates who had been affiliated with the military who carried out the genocide against the Maya. While there was controversy about the veracity of her accounts of her families' role in the counterinsurgency against the government (Arias 2001), Menchu's reporting of Mayan cultural values and practices was not contested. The Mayan people do not believe in abortion: from the moment of conception, life is thought to be sacred and the people in a community see themselves as obligated to treasure the pregnant women, protect and support her, stopping to greet and pray for her when they meet her in the village. Another important and most credible diary by a Mayan, the diary of Ignacio (edited by James Sexton), confirms the Mayan cultural opposition to abortion, which is deepened by the fidelity of many Maya to the Catholic Church (Ignacio 1992).

Customarily, a Mayan woman would be married in her early teens and bear many children during her lifetime, many of whom would die from malnutrition or disease.

The recent history of profound genocide against the Mayan people continues to be a source of intense conflict and tension in Guatemala (Sanford 2003). The UN was involved in the peace accords between the government and the Mayan insurgency, but terminated its involvement in 2004, citing continued profound problems with racism, corruption, and internal violence. The previous president and vice-president (Portillo and Reyes respectively) were charged with embezzlement, fraud, and corruption, and Portillo fled to Mexico and was still to be extradited in 2007. A World Bank report in 2005 identified Guatemala as the most unequal country in Latin America. The country's disorder and violence were aggravated by recent efforts of drug cartels from Colombia to seek a stronghold in Guatemala, but the violence was still promulgated by government 'security' forces, as noted in a respected U.S. security agency report: "Criminal gangs will target wealthy local business personnel and occasionally foreign nationals, especially in the capital Guatemala City. Robbery, burglary and kidnapping predominantly affect

Guatemala City, but are widespread nationwide. The involvement of current and former security forces members in serious crime such as drug-trafficking is a growing problem” (Group 2007).

Currently, in terms of children’s quality of life, Guatemala ranks 19th in the world in the frequency of infant mortality, and its children have some of the worst nutritional status in the region: UNICEF estimates 76% of Mayan children live in profound poverty, and one-half of Guatemalan children suffered from chronic malnutrition in 2006 (UNICEF 2009).

Twins

We received a call from our adoption agency in February, 2007, that twin boys had been borne in the Mayan city, Mazatenango, relinquished for adoption, and that we could adopt them. We were overjoyed. Shortly thereafter we received their photographs, and fell in love with them immediately. We learned more about the birth mother from her photographs and statements to the social worker who interviewed her. She worked making tortillas and earned \$40 a month. With two older sons for whom she was providing, but whom she could not afford to have live with her, and without a husband, father of the twins, or other family members to help her, she wanted her sons to have a better life in the United States. It was not surprising to us that a single woman with no family supports living in such grinding poverty, at the brink of her resources in caring for two sons already, and likely with a family history of brutalization during the genocide, would find the prospect of caring for twin babies insurmountable. And there was also the concern about the boys having been born out of wedlock, and the shame that might well have attended their residing in their community (Ignacio, 1992; Menchu, 1984). A mother residing in the United States and faced with such stressors might certainly have opted for adoption.

Their birth mother’s choice of names expressed her expectation that they would be traveling and her hope they would distinguish themselves. As is customary in Guatemala, both boys had the same first name, Alejandro (Alexander). Jose (Joseph) looked from his birth portrait to be reflectively examining his world and already thinking about it. Fernando (the name means, ‘one who travels’) seemed to be born smiling. We wanted to keep their birth mother’s names for them, out of respect to her and their heritage, and yet also we wanted to offer them names from our families to make it clear that we offered them a family completely. Accordingly, we named them David Jose and Donald Fernando. We were told we would likely be able to bring them home in late spring or early summer.

When we considered going to Guatemala to visit them, we learned that the U.S. State Department was strongly advising against travel to Guatemala: it was impossible to prevent violence against tourists because police were involved in the worst forms, which included surrounding busloads of tourists and demanding money; puncturing tires in rental cars and then ambushing tourists on the road when they tried to fix the tires, and kidnapping infants awaiting adoption to collect ransom money from the desperate adoptive parents. Police would go to the hotels where adoptive parents were caring for their children, demand the children, and tell the parents they had to provide thousands of dollars to get their children back. While adoptive parents and their potential children were certainly prime targets, the violence permeated all aspects of society: In the

parliamentary elections that were going on in the summer and fall of 2007, 40 candidates were murdered. The remaining candidates had to talk behind bullet-proof shields.

Trick or treat for UNICEF?

Ironically, the degrading and often violent racism (by ‘Ladinos,’ the ruling Spanish-speaking people, against the Maya) still endemic in Guatemala, was illustrated in an incident of international adoption. During the time the adoption of our sons was in process, the President of Guatemala, Oscar Berger and his wife, decided to adopt a child, but instead of adopting a Mayan child, they adopted a Caucasian child from Russia. Their decision was considered unremarkable in Guatemala. Also that Fall, UNICEF representatives in Guatemala allegedly gave President Berger (via a donation to his wife Wendy’s organization) 28 million dollars if he would support an end to international adoption and instead build orphanages (Luarca, 2006). Berger left office in early 2008 without there being any accountability about the money and without any significant investment and improvement in conditions for orphans in Guatemala.

We expected that our adoption would follow the traditional timeframe. The birth mother and the babies had to have their DNA tests confirmed by a U.S. source to ensure she was their parent; the boys had to be made available for adoption in Guatemala; if no one arose to adopt them, the case had to be passed through the Guatemalan Family Court; and finally the adoption had to be validated by the Guatemalan governmental agency, “PGN.” We anticipated that the adoption would occur in summer, 2007. In late summer our adoption agency told us that there had been an abduction of twin boys and that although the abducted boys were not our sons, nonetheless our boys’ case was being delayed in PGN because extra evaluations were needed given the abduction. Then we learned from our adoption agency in August that the boys had been harbored in three foster homes, two of whom were replaced because the agency had been unsatisfied with their care. I was devastated to learn about the shifting foster mothers since as a child therapist who has treated young children suffering the effects of multiple foster placements (which can range from profound disorganized hyperactivity to elective mutism), I had some sense of what it means for a baby to repeatedly lose their mother figure. Just when their emotional life and identity is being formed and looking ardently for a secure foundation and stable arms to embrace, to suddenly be torn away three times in succession is traumatic at a level so profoundly disorganizing it can hardly be put in to words. Pictures of the boys we received in August confirmed our fears, as the boys looked scared and were not smiling. We passionately expressed our concerns to our agency, and started trying to advance the adoption process. But events in Guatemalan adoption were becoming increasingly chaotic, as UNICEF and other groups stepped up their pressure on the government to abolish international adoptions altogether, despite the efforts of advocates of international adoption, including the director of our agency, who testified in Guatemalan court about procedures to ensure legitimate international adoption.

In September I began weekly calls to the Guatemalan government agency responsible for verifying and finalizing the adoption, “PGN”, to try to understand the nature of the hold-up. In late September I learned from PGN that the twins’ case was held up in the Minors’ Section (a special section for problematic cases, especially where the birth mother is a minor). I immediately contacted the adoption agency, who spoke

with the lawyer assigned to our case. He informed us that it was held up in the Minor's Section because a police report was needed to prove the children were not the abducted twins.

The Minors Section of PGN was headed at that time by Josefina Arellano, a known critic of international adoption reputed to have said, "It would be better if the children were dead than that they were adopted." This officially hostile bureaucracy subsequently sent the case to the police for further investigation. Aware that with the timeframe for adoptions coming to an end the boys might be consigned to indefinite orphanage placements, we decided to hire another set of Guatemalan lawyers, highly recommended by other parents, to advocate for advancing the adoption through the PGN.

Meanwhile, we learned that tensions in the adoption community in Guatemala were so profound that one adoption lawyer, a human rights advocate who supported facilitation of Guatemalan adoptions, had been held hostage in PGN and threatened for several hours (Luarca 2007). Our fears at the time could not even comprehend how bad things could have become: as of this writing two years later, 700 children who were supposed to be adopted as infants still languish in orphanages in Guatemala, and their adoptive parents have no recourse as the bureaucratic delays put up one obstacle after another (Aizenman 2009).

At the last moment, our adoption lawyer obtained the police report on October 24 and the boys' case was released from the Minor's Section. It was finally released from the PGN a month later in early December. Thus Donald Fernando and his brother, David Jose, were, in Guatemala, legally our sons as of December 5, 2007, when their birth mother came to court again, this time to sign her final relinquishment.

They were legally our sons in Guatemala days before a new law was signed into effect by the Guatemalan Congress (and the President, who allegedly received a 28 million dollar compensation from UNICEF before he left office (Luarca, 2006; UNICEF acknowledges advocacy for the passage of Guatemalan Law 77-2007 On Adoptions, <http://www.unicef.org/infobycountry/guatemala.html> [accessed 1/22/2010]). While stating its intent was to comply with the Hague Convention, Decreto 77-2007 created a new adoption processing bureaucracy, prohibited any financial benefit to anyone involved in an adoption, and mandated that all adoptions be national before they became international. It has in effect posed insurmountable obstacles for completing adoptions in process and prevented new international adoptions.

Of Diseases, Physicians, and a Hospital

Meeting our sons

Awaiting the children's appointment to be screened by the United States State Department in Guatemala City for their visas, which was the last step, we learned that one of the babies was sick with a cold and in the hospital. Given what we knew about the vulnerability of orphans to dying even from measles, we decided to go immediately to Guatemala. We arrived 36 hours later, afraid in the airport and while taking the cab to the hotel, but safely.

The next morning, in the lobby of the hotel, we had the joy of meeting David Jose for the first time. Within a minute of starting to get to know David Jose, there was the terrible shock of being told by the foster mother that Donald Fernando was in intensive care, on a respirator, having suffered acute convulsions due to meningitis 10 days

previously. We frantically called our adoption agency, who had no idea what had happened. After they made calls they confirmed what the foster mother said. Donald was in the public hospital in Guatemala City. Because he was not yet legally our child according to U.S. law, we could not admit him to any other hospital in Guatemala or have formal responsibility for his medical care. We would have to do the best with what was available where he was, and in any case, he was too ill to be moved at this point.

Bob immediately went with our translators, Alfredo and Claudia (to whom we are eternally grateful) to Roosevelt Hospital, akin to Cook County Hospital in Chicago, or any large urban hospital serving indigent people, but correspondingly under-resourced in Guatemala. Upon Bob's return he told me that Donald was in a coma, hooked up to a respirator, on a feeding tube, and tied down. "Are you sure you want to go?" he said. "It's really hard he looks like Jesus Christ on the cross."

Donald was stricken with streptococcus pneumoniae which, as it often does, infected the coverings of his brain, a syndrome termed bacterial meningitis. The worst side effect of the disease is that the blood vessels that supply oxygen to the brain constrict uncontrollably. In the absence of blood supply, cells in many regions of the brain begin to die, which in turn causes swelling in the brain that squeezes the blood supply even more. This process causes extensive, lasting brain damage, and is fatal if steps are not quickly taken to halt it. Current estimates are that 14.5 million children are stricken with serious pneumococcal disease worldwide, resulting in over 820,000 deaths (the majority in non-HIV positive children); about 11% of all deaths of young children are caused by pneumococcal infection (O'Brien, Wolfson et al. 2009).

I went to the hospital. To get to Roosevelt Hospital one goes through winding streets of Guatemala City, up and down hills, and then through a marketplace and streets packed full of Mayan people, women in long striped dresses with lace tops, their children in slings on their backs or holding their hands, the men, some wearing ponchos, in darker colors. The people were selling primarily foodstuffs, pottery, and greens, plants with huge green leaves that I didn't recognize, some waiting by the side of the streets, others in long lines, waiting for a bus perhaps, something I didn't have time to identify as we drive past. Then we went through a public park – unkempt compared to the hotel district, with huge overhanging tropical trees and wild brilliant flowers sweeping overhead. The driveway turned into a semi-circle and there was the hospital – dirty white, many windows nonexistent and covered with newspaper, huge and dilapidated.

Bob pointed me to the main door – only one of us could go at a time and the identification process was complex. Donald Fernando could not be admitted as an orphan awaiting adoption because of the concern he would be discriminated against and not receive care. So we were not listed as his parents, even though in fact under Guatemalan law we were. I went to the social worker's office with the patient ID card with Donald's name on it and waited for her to get back. The waiting room steadily filled with Mayan people. That would be how it would go for all our visits over the next month: only Mayan people at that hospital. Alfredo and Claudia told me anyone with money went to different hospitals. When the social worker came back, she looked like one of the Spanish-speaking elite (or Ladino). I spoke to her in my elementary Spanish, and she was openly hostile, "Only his mother can come." I showed her that according to Guatemalan law, I was Donald Fernando's mother. She looked at me with undisguised hostility and waved me towards the guard who, also Ladino, looked at the card and then

told me to go upstairs. I walked through winding institutional blue hallways, past many Mayan families visiting their children; the hallways wound and turned without signs, and I was unsure if I was going the right way until some doctors pointed me towards the pediatric neurology intensive care. The door to the unit was closed and there was a waiting room with parents, many of whom were crying. There was Donald's foster mother, who came up to me with tears in her eyes and embraced me. I went into a large room with children all around the perimeter, all hooked up to various machines so they seemed buried in tubes, all beeping in various ways, with notably few nurses.

I asked for Donald Fernando and they pointed me to his bed, and there he was, a tiny, tiny baby who looked like David but with hair even darker against the yellowish white sheet, his skin paler, his eyes closed. And he was stretched out as if on a cross, restrained (they later told me it was because as soon as he woke up he would try to tear out the tubes), the IVs in his left arm, a feeding tube and respirator controlling his breathing, keeping him alive. I remembered the comatose patients from my time as chaplain-in-training and medical social worker and hoped that perhaps he knew I was there. All I could do was reach for his tiny hand and pray and the tears started coming down my face. I stayed that way and finally someone who looked like a resident came over and I asked how he was doing in Spanish – 'the same.' 'His condition is grave, they are unsure what will happen. Right now he can't breathe or eat for himself and if they reduce the high dose of anti-seizure medicine, he has terrible seizures.' I felt numb and shocked and look around and realized how many other children were there in dreadful condition, some who looked like they have terrible tumors and I couldn't look any more. I focused on Donald and then the brief visiting hours were over. I went out into blinding Guatemalan sunshine and could hardly talk as we went back to the hotel.

Fighting for their lives

So every day we went back to the hospital. I would take care of David in the morning while Bob went and then I would go for the afternoon. The guard obviously came to know me but also obviously did not want to have any kind of relatedness and asked for my card very officially every day. I got used to being 6 feet tall and blonde, waiting in a long line with Mayan families who are so terribly malnourished and impoverished. But not one was cruel or even stared; if we made eye contact, they just returned my nod and smile.

Bob, conferring with doctors with the help of our translators, learned that they had not given Donald steroids during the critical first hours of his illnesses. Those might have prevented some of the swelling of his brain. The steroids were more than they could pay for in a public hospital. One day I was stroking Donald's hands and feet and noticed that while his right hand and foot responded, his left did not. I asked the resident and he said 'Yes, it is likely his left side is paralyzed.' How long will it last? They don't know. Does he feel anything? 'Yes, he can feel pain.' I thought, that is terrible, he can't move but he doesn't have the blessing of numbness.

Bob, being a brain scientist, could read MRIs and knew Donald's syndrome, having taught physicians how to read MRIs and done thousands of dissections of brains of humans and animals. Bob learned that they did not do an MRI scan on Donald because they did not have the funds. It would cost \$30. He also found out that Donald needed a medication that would cost \$9. We paid for the MRI and the medication. Donald had lost 20% of his body weight. Adults can die when that happens, let alone

babies. Our lit search late at night after David was asleep (when the internet was working; the internet, cell phone, and hot water were all very unreliable) indicated that infants with his presenting symptoms (severe seizures, comatose) have a 33% rate of mortality from this disease and if they recover many are severely disabled with epilepsy, cerebral palsy, paralysis, and retardation. In developing countries bacterial meningitis and encephalitis are not uncommon, especially in the winter months, often resulting from streptococcus pneumoniae bacteria, against which vaccines are used in industrialized countries (for instance, (Lovera and Arbo 2005; Natalino and Moura-Ribeiro 1999; Siddiqui, Rehman et al. 2006; Selim, El-Barrawy et al. 2007)). The next day our translators told us their children were vaccinated against the pneumococcus disease because it can run rampant in Guatemala. We thought David and Donald had received all their necessary vaccines (and had paid our adoption agency to ensure they received them).

We frantically tried to figure out what to do. My family was calling every day and my sister said her husband's brother is a pediatrician; they called him and thank God, he did his residency at Roosevelt Hospital. He speaks fluent Spanish. He agreed to help us by having a conference call with Donald's attending and Bob. So we arranged that for shortly after Christmas and prayed that our cell phone connection would be working.

Christmas Eve Bob came back from the hospital, furious. He learned from the residents that Donald (and, we assumed, David) had not been vaccinated against pneumococcus and many other childhood diseases. Apparently the lawyer and doctor responsible for their care were trying to save money (the vaccine costs \$25 in Guatemala). The translators confirmed their friends called the pediatrician "Dr. Cheap" because he was known to skimp so badly on care. Donald's condition still appeared dreadful, he was still in a coma. We called the adoption agency, and to their credit, the assistant director was horrified by the news and stayed in touch with us by cell phone for the remainder of our stay.

Then Christmas day when Bob was there, Donald woke up. But he would not suck. Bob came back and said, "If he doesn't suck it's all over they'll have to put the feeding tube back in and the risk of another infection is very high..." I frantically thought about what I had learned about babies in medical emergencies – how they can lose their will to live because the physical pain is such a shock it disrupts any sense that they can feel good and like a suicidal adult, they just stop eating or drinking. What could we do? "Let's find lollipops" I said, thinking that the burst of pleasure on his tongue might help him the way it helped my depressed child psychotherapy clients. So we looked around the city to find a store open on Christmas Day that would sell lollipops and Bob took them to Donald. When Bob came back, he said that after a few hesitating moments Donald started to suck. But it was clear it was hard for him to move his lips and when they then tried a bottle, he started to choke. Bob said, he may not be able to swallow, his swallowing muscles might be paralyzed too.

Meanwhile we were caring for David, who had responded to all the trauma he had experienced with the curiosity and activity of a baby determined to learn about what was going on around him and to make the best of it. David was incredibly active, curious, and social, standing up in his crib every morning to greet the day and us with a smile and a characteristic "kkkkk" sound that he used to initiate any social interaction. He crawled everywhere and was thrilled when I held his hands to help him learn how to walk. He

clung on to Bob and me as though he knew from the beginning that we would love him forever and he had just been waiting for us all that time.

But the day after Christmas, David suddenly vomited and got explosive diarrhea and fever. In a panic I contacted our adoption agency, who said I needed to work with their pediatrician, even though we had lost all trust in him, as he was the only pediatrician they knew and could recommend. The pediatrician came to visit us in the hotel and told us there was a rotavirus outbreak among Guatemalan children and this was no doubt it. 'It does not have to be serious, we have to feed him pedialyte and if he vomits again we will admit him to a hospital.' Sitting on the couch with me he said to me, "you know your other son, he can grow up to be normal, I've seen many children grow up to be normal who went through that." I started to cry with relief. I translated for Bob, who was horrified and said to him, "How can you lie to us like that?" And from the pediatrician's expression, I realized he was lying.

Then we were worried about David, how could we trust this pediatrician with his care? But we didn't know anyone else and during this holiday our translators' pediatricians were not available either. Bob recalled that while I was visiting Donald, he and David were playing in the park and a little girl wanted to share her ice cream cone with David, which he did... no doubt it was there that he contracted the highly contagious disease. The doctor said to be careful of ourselves, we could catch it too if we did not receive a rotavirus vaccine as children. We didn't remember ever being vaccinated for rotavirus. I looked it up on the internet and it is a protracted diarrhea syndrome with grave risk the baby can become dehydrated, especially if they vomit. Rotavirus was another vaccine that the boys should have had but were never given. The vaccine is effective in preventing this disease, which rampages through developing countries primarily during the months of November - February. More than a half a million children die every year from rotavirus, most in developing countries (Tanaka, Faruque et al. 2007; Parashar, Burton et al. 2009). As of 2008, WHO reports that neither pneumococcus nor rotavirus are part of the normal publicly-funded vaccine schedule for children in Guatemala, although U.S. children routinely receive those vaccines (http://www.who.int/immunization_monitoring/en/globalsummary/countryprofileresult.cfm).

We were able to have the conference between Donald's attending physician and my brother-in-law's brother. He reassured us that the treatment Donald Fernando was getting was, at this point, on a reasonable course. We shared our concerns about David and he thought rotavirus was a likely cause and also emphasized to seek immediate hospitalization if David vomited, stopped drinking pedialyte, or his diarrhea did not abate within a week.

I teach classes on global social work and we talk about structural violence based on James Farmer's excellent work: the physical suffering of poor people caused by the deprivation of basic medical care, contributed to frequently by the exploitation of poor countries by those more wealthy, and by the global imbalance in resources (Farmer 2003). I realized my sons were victims of structural violence, as are so many other children. Meanwhile David's fever went up and he had constant diarrhea; I kept him near the bathtub because it was so painful if the extremely acidic diarrhea had any contact with his skin. David cried because he was so uncomfortable and I found myself unbearably fearful of losing David too. I started to cry at the same time that I was

frantically praying that David would be spared. I realized how much I already loved him more than myself – as someone said about her love for her child, “its like your heart is walking around outside your body.” As I was hugging him and crying David looked up at me in a puzzled way and expressed the most that he could at that time, stroking my hair with his hands.

By the next day, he had not vomited again. David drank down the pedialyte as avidly as if it were the best milkshake around and again I was struck by his resilience. He cried when the diarrhea bothered him and was weak but otherwise hung on to me with great determination and retained his insatiable curiosity. He was more uncomfortable at night and I put him near to me in the very large hotel bed so I could tell immediately if he became too sick. Then of course I started to feel sick myself, but it was fortunately a weaker version of the illness afflicting him.

After several days it became clear that the worst of the fever was over; the diarrhea continued and we were told, would for a week, and for another week he could not drink milk-based products because of the trauma to his digestive system. So we bought a brand of non-milk based formula and fortunately David took to that too... what happens to the children whose parents cannot afford pedialyte and special formulas?

Donald got out of intensive care on New Years Day. We went to see him on the pediatric neurology floor, in his hospital bed, which looked like beds from movies in the 1930: dingy metal, tiny, rickety, the sheets worn and yellowed. The children on his unit had terrible conditions, most were in beds or wheelchairs, paralyzed, trembling, some with heads bandaged. Now that I could hold him I discovered Donald had raw bedsores all across the back of his head and a terribly painful diaper rash all over his bottom. Neither of these would have happened in a hospital for more privileged children, and they were excruciating for him. The hospital only allowed children two bottles of milk a day because that was all the hospital had money for, and they would not allow us to bring Donald more. They also had a shortage of water and we could not compensate for that either.

Donald had two roommates who were older than he. Their parents spoke only Mayan, which was nothing like Spanish so I couldn't understand them, but they were very friendly and showed me where all the necessities were for parents (where to put dirty diapers, etc.). There was a room where the parents kept their things: there were so few nurses, the parents spent the nights with their children and slept on the floor. We could not stay the night as we were not officially his parents, but we could support his foster mother in her desire to do so. When Donald started crying, I picked him up and comforted him and sang to him and I saw the Mayan mothers point to me and nod approvingly to each other. Over the next several days we parents found ways to communicate, and when Donald's seven year old roommate had a birthday, we brought small gifts from the hotel and he and his parents were thrilled. I noticed the Mayan parents were permissive and greatly affectionate with their children. When the siblings visited they jumped around and played and seemed to not have any fear of their parents.

While the Mayan people we encountered were uniformly supportive of our adoption, there was a significant contrast in our experiences with the non-Mayan people in Guatemala (with the exception of our translators). Alfredo and Claudia warned us that we should not leave the few blocks around our hotel, for fear that we might be harmed or David kidnapped and held for ransom. One time Alfredo and Claudia took us to the

Guatemala City Zoo with another set of parents and their adopted baby. Seeing me with David, a strange Ladino man came up and made some derogatory remarks in Spanish, evidently assuming I would not understand. When I responded in Spanish that my son was a marvelous boy, he looked nonplussed momentarily but then mockingly said, “he looks like you...” We turned and walked away.

Exit

Zuleima’s words of hope, an honest physician’s prognosis

Shortly after New Years, the Ladino lawyer who processed the adoption (and hired the pediatrician who did not give the boys their vaccines) came to the hospital to have pictures taken for Donald’s passport. Bob and I could not figure out how they thought Donald could look healthy in the pictures, but we saw how he was posed and indeed, he did not look anywhere near as ill as he did in person. The lawyer’s only interaction with Bob was to acknowledge his presence with a nod, and we realized how thoroughly unscrupulous and uncaring he was of his tiny client who had clung so determinedly to life.

Able to take in a bottle, Donald was discharged from the hospital on his birthday. We celebrated with a Sponge Bob piñata and dinner with Alfredo and Claudia and the foster mothers. Donald was in a baby carrier, asleep most of the time, sweating profusely, trembling with myclonal seizures and crying when he woke up. He drank from his bottle, but just barely.

A few days later we took Donald outside in a baby stroller for his first walk in months, and ran into Zuleima. She was a Mayan woman we become acquainted with who sold her handicrafts outside of our hotel room. When she saw us with Donald she was most supportive. She had not been easy to get to know: Clearly an astute business-woman, she spoke English, Spanish, and Mayan, and sold her work as well as those of others without any bargaining allowed. When I had realized that I would need a baby sling for David (as within a day he had not wanted to be separated from me by more than a few feet), I talked with Zuleima but then finally purchased from another woman one of the large blankets Mayan women use as baby slings (it cost half what Zuleima charged). The next day Zuleima saw me with the blanket she had not sold to me and offered to help me tie it as the Mayan women do. While she was doing that she commented, “Oh it’s damp, you had to wash it, it wasn’t new?” I nodded and she said, “Mine are new.” “Yes,” I had said, “But this cost a lot less. I don’t know how long we’ll be here, he has a twin brother in the hospital who is very sick and is needing medications and care.” Zuleima’s expression of concern had deepened and she expressed her hope that he would recover. Now, seeing Donald with us but obviously still so ill, she escorted us on a walk around the block, full of support, saying, “It is so wonderful you can take him to the U.S. and keep them together, they will know how to help him there” (her support of our adoption was common among the Mayan people we encountered, and was also documented in interviews with Guatemalans, Wilson & Gibbons, 2005).

That night Alfredo and Claudia said they felt badly for us that the pediatrician had been so dishonest and that they could help us to bring Donald to a pediatric neurologist they believed to be one of the best in Guatemala City. Deeply grateful, a few days later we went to Dr. N.’s tiny storefront office with Donald and David. We waited with other parents with children suffering from terrible neurological conditions – some clearly

retarded, some with crippling cerebral palsy. Dr. N. examined Donald and then said to us, "I have to tell you, I saw him in Roosevelt Hospital also. He should have had the vaccine for pneumococcus, it would have prevented this and it is commonly given now for children here. It's amazing he is alive. I saw his brain scans. You understand the syndrome (Bob nods but he explains it to me). The infection caused his blood vessels in the brain to spasm, they cut off oxygen to the brain cells and then the brain reacts by flushing out with fluid. The brain swells and there is more damage. There are now giant holes of water where there should be brain cells. He has lost so many brain cells, most likely he will never be able to swallow, to talk, to feed himself. He'll never be able to walk or even use his arms. He will be deeply retarded and probably never be able to recognize who you are." I said, finding it hard to believe the doctor, "It seems he knows us in a way now, he looks at us deeply for a long time like a younger baby." Dr. N. responded, "Yes but he has to do that because he can't make sense of anything he sees. He might recover something but it would take a miracle. I have seen miracles, believe me, but they do not happen often." Dr. N. refused to take any payment from us and also agreed to be available in the future for help if we should need it. We were both impressed by Dr. N.'s obvious honesty, skill, and commitment, shocked as we were by what he told us.

At first Dr. N.'s prognosis didn't sink in. It couldn't be that bad. But then we realized that if Donald did not get significantly better, it would be as bad as Dr. N. said. He was functionally paralyzed, could not even hold up his own head and his limbs trembled with seizures when he was awake. He cried continually and could barely stop in order to take a few swallows of food, and then spit up half of what he swallowed. Bob and I got up to feed Donald at night, and it seemed we were up every two hours. But one night we each thought – gee it looks like more of his bottle is gone than when I got up the last time. And when morning came we realized that Donald was actually waking up every hour, and we were unknowingly spelling each other and had the illusion he was waking up every two hours. When David crawled over to Donald and patted him, Donald did not respond. It seemed David did not know him, except that David did keep trying to pat him, but he related with Donald more like Donald was a doll than another person, understandable since Donald didn't really respond in any way. We noticed, however, that Donald felt physical pain and expressed more distress if he was in his crib and we were all together at the table – he was happier being near us and didn't like to be alone.

Devastation and departure

That day and the next we were frantically thinking: We were assigned by the consulate visa office to adopt them both at the same time, and had perhaps the last embassy interviews we could arrange to get the boys out before the adoptions were terminated by the government. We thought, the lawyer must be thinking he can bribe the U.S. consulate pre-screening doctor to sign that Donald is healthy. But the consulate office staff also interview us with our adoptees and we won't lie and can't imagine Donald would pass it. What would happen to Donald and to our adoption of David then? In part to prepare for the consulate's questions about whether Donald would drain public funds in the United States, we tried to find out what kind of care Donald could get in the U.S. in his condition. My insurance did not cover long term care for children, which was what Donald's probably need for several rounds of tube feedings would require. I checked institutions in Chicago and found it costs hundreds of thousands a year, which

we did not have. Phone calls to our adoption social worker and accountant confirmed that we would be falling into a hole in the U.S. where there was no financial support. I found myself realizing that if I lived in another country like Finland, where there are better supports for families caring for children with special needs, there would probably be some way to bring Donald home. But I don't and in the embattled context of Guatemalan adoptions it was clear that all other international options would be blockaded for Guatemalan orphans indefinitely. Zuleima's supportive, hopeful comments took on a tragically ironic ring.

I don't know how to describe what the next days were like except to say that there was an actual earthquake in Guatemala city – the hotel shook, the lights flickered on and off and it seemed like only a very minor event and not the least bit frightening because I was feeling so stricken. We had been in Guatemala a month, it seemed like years. All I could think about was what would become of Donald whom I had grown to love, and if we couldn't bring Donald home somehow, how would David feel about losing his twin?

And then we didn't really have a choice. The consulate doctor put off Donald's appointment. Bob got up and walked to the consulate visa office early each morning, telling them, 'we need an appointment for our adoption of David.' They didn't pay attention. Finally they let us know a date over email and it was three weeks away. We couldn't wait that long, not the way the government was terminating adoptions. Planes out of Guatemala were full and we had reservations to depart in a few days. It would be impossible to change them. I insisted on talking to the consul myself and pleaded. "Everyone else is in your situation and some have waited longer," she says. "Not all of them have patients at home or a son who has been in a coma here," I say. She finally agreed, and gave us an appointment for David's consulate visa review the day before our plane was scheduled to depart.

We went to the consulate visa office with David just after dawn. The office was full of babies, most of whom were younger and quiet or sleeping. David characteristically was wide awake, wanted to see everything and crawl everywhere, and I entertained him singing songs, "We're off to see the Wizard, the wonderful Wizard of Oz." Certainly, we were not in Kansas anymore. David decided to be a one-baby greeting committee, sitting by the door watching how it opened and closed and smiling at each person who came in. Finally after five hours of waiting we had our interview and obtained permission to bring David to the U.S., with the assumption Donald would have an interview when he was well enough to travel. We couldn't share with the consul Dr. N.'s opinion.

That afternoon, numb with exhaustion but unable to rest, we went to the main square in Guatemala City. Alfredo and Claudia urged us, "You should see it, you haven't seen anything of Guatemala while you've been here and all the other parents do..." so we went, carrying our babies. David, soon to be an immigrant, was moving constantly and looking everywhere, and Donald, whom we would have to leave in Guatemala, looked tiny and exhausted by comparison and did not move in my arms. We saw a wall where the names of people murdered in the genocide were inscribed, like the Vietnam Memorial in Washington. Even more names are being added all the time as they dig up the graves. I thought, perhaps the boys' birth mother's family members are listed on that wall. How many orphans are not on that wall, casualties of infanticidal neglect that is no doubt even more common among orphans not on the track for adoption? We went into the church and at last it was dark and all I could do was cry because I could not fathom leaving

Donald there. Only three more hours with him. We went back to the hotel and I couldn't stop the tears from running down my face.

The pediatrician showed up unexpectedly and it was clear to Bob and me that he was there to try to convince us to stay and take Donald back with us in a few days. Bob became angry at this: 'How can you say the consulate would pass him through?' The pediatrician could say nothing to this. He left shortly thereafter. I felt like I was sleepwalking as I showed the foster mother Donald's medicines, demonstrated how to get it down his tiny throat despite his protests, which food he liked the best, how to treat the terrible bedsores on his head and diaper rash on his bottom. And then they had to take him.

The next day we went to the airport and there were other adoptive parents going through the lines. An ecstatic family had a thirteen year old Guatemalan girl who looked like she was Cinderella at the ball, all big eyes and smiles. We were all afraid, until we got through U.S customs at the other end of our flight, that something would go wrong again and after all this we would lose our children.

The flight took off and I had a sense of freedom for David and a terrible sense of doom about Donald. When we landed on American soil I felt a returning sense of determination and realized how important it was that David would not have to grow up in a country where his people were so hated by their own government that they murdered them by the hundreds of thousands and are still murdering their children in various ways, primarily through terrible deprivation and neglect.

Limbo

In the U.S. that winter and spring I felt my heart divided. There was the joy of caring for David: his first snow, his first steps, his first time in the park in the Spring. David was fascinated with a TV show called "eebee baby" where the babies play with other babies doing baby things like peek-a-boo and rolling balls down ramps. We got him the eebee baby doll and he called it and the show, "Beebee". It was a life-size baby and he carried it everywhere.

There was blizzard after blizzard that winter and it seemed that my soul was getting blanketed with preoccupation with Donald. We obtained our license to be adoptive parents of a child with special needs. We contacted our lawyer and put pressure of all kinds on the adoption agency to monitor care for Donald in Guatemala. We kept in touch with Alfredo and Claudia who let us know, via the foster mother, that Donald had had to be rehospitlized and put on a feeding tube because he could not eat, and our agency had not told us. We let the agency know and remonstrated with them, 'how could they not tell us, we are his parents!' We learned from the translators that Donald had still had no physical therapy, despite the pediatrician's promises to arrange it. But then the lawyer changed foster mothers so we could not get reports any more through our translators. So we ramped up the pressure on the agency by writing the U.S. consulate in Guatemala of our concerns, including Donald's need for physical therapy and our need for reliable medical evaluations and reports that would be sent directly to us. Our agency then assured us they would be done. An MRI was done of Donald's brain and we received the report in early March: There were many spaces where he had only air and water where there should have been cortical brain cells. The neurologist concluded that

Donald would be significantly retarded and have many other problems as well that could not be foreseen based on that test.

I tried to find social services to care for Donald in Guatemala if we could not adopt him, and came up with nothing of the intensity to match his needs. I was thinking about trying to locate a convent or monastery somehow. I realized that in his condition, given the state of services there, he might either die or else live a life in some dreadful institution in terrible pain. I could not fathom how to talk with David about his brother when he reached an age when he would need to know about him. I finally said to Bob, 'I have to go back there, I can't just leave him there.' 'Have them send us a video,' he said. And he wrote down the eight things he wanted the agency to have Donald do for the video: feed himself, sit up, etc. We waited and the first video came on a memory stick that would not work in any of our computers. We waited and received pictures of Donald sitting and Bob was angry, "these must be faked." I said, "I have to go back."

And then in mid-April a video came, we could run it on our computers, and there was Donald. He was a lively baby, looking like David's twin, feeding himself, smiling, in a baby walker and communicating his distress because he wanted to go outside and was frustrated. There were pictures of him standing. And we said, 'We have to bring him home.' We called the agency, who said that he passed his interview with his consulate doctor and within a week there was an appointment for us at the consulate to get Donald's visa. We didn't know exactly how this was accomplished but later saw the lawyer's documents said we were adopting a "completely healthy infant boy." Bob said he would tell the consul the truth, but by that time, it appeared Donald could do enough that there was a good chance he could pass the consul's exam as a special needs child who was still adoptable. Bob went to Guatemala to retrieve Donald while I stayed to take care of David because we did not dare take David back.

Would Donald remember us? From Guatemala, Bob called home and told me that when Donald came in with his foster mother and her family, they handed Donald to him and Donald grabbed him tightly, hugged Bob completely, and would not let go throughout their meeting. When the time came to say goodbye to his foster mother and she wanted to hug him, he would not let go of Bob, hanging on fiercely as his former caretakers said goodbye. Bob said, "Donald is totally winsome and charming, he smiles at everyone. He's paralyzed and can't move but he's eating like a horse even though he drools and his food spills all over, and everyone loves him." He also said that the hotel he stayed in (which had not been available during our first trip), which was probably the most often-used hotel by adoptive parents, was in disarray: facilities and rooms that had been set up for families were being dismantled, staff were losing their jobs, and everyone was wondering what they would do to make a living now.

Reunion

What would it be like when Donald came home? I talked with David for the three days Bob was gone as we bought an extra crib, baby clothes, other things Donald would need for encouraging his ambulation. David could not talk yet and I had no way of knowing if he remembered his brother or understood what I was saying. Then the last day I was putting things in my red shopping cart and David became excited, pointing. I put him down from the cart and little 15 month old David immediately picked out his own (toy) red wagon and, having gotten the idea of what happens in shopping, went around

the toy department starting to pick out toys he wanted and putting them in his little wagon. Did he understand his brother is coming? We didn't know. We went home, the hours and minutes ticked by and then Bob called, "I'm outside, we're home..."

Donald got off the elevator in Bob's arms and all questions about whether they would remember each other were instantly gone. David yelled, "Bee beee" (the name he had called his eebee doll) the instant he saw him. Donald for his part yelled "AAAAAAHHHHH" and reached out, from Bob's arms, for his brother. We put them on the couch together and for hours they were ecstatic, putting their fingers in each others' mouths, David often putting both hands over his heart as though it would burst with pleasure. They hugged each other, laughed at jokes only they could know... They peered into each others' faces, serious and then laughing. They touched hands and feet and patted each others' heads. Donald's left arm was paralyzed and he couldn't move from his seated position on the couch facing David, but he nodded his head enthusiastically and reached constantly with his right hand to stroke David. I had tears running down my face and kept taking pictures, the moments were so precious for them to have forever. Too young to ask each other, 'what happened to you?' they had their own vocabulary of reconnecting... Their reunion went on for more than three hours but seemed like lightning, and then Donald became exhausted.

That night David immediately jettisoned the eebee doll to a corner and David and Donald became inseparable. Since Donald couldn't crawl or walk, David pushed and pulled him places in the red wagon. He helped him drink his bottle, helped him eat, babbled to him and they laughed together constantly. Donald took to his baby walker and could jet up and down our hall, speeding after his brother so they both ended up at my side, laughing, wherever I was. Donald was ticklish and chortled with glee when we tickled his tummy.

Towards Recovery

As the days went by we saw the challenges Donald was facing: he seemed greatly affected by his powerful anti-seizure medications and sometimes looked quite disoriented. If he was put down out of his walker, he could only sit and was immobilized. It was clear that somehow once again the lawyer had rigged the April pictures of Donald standing. Donald got a high fever the first weekend back and we took him to the emergency room, terrified he would have a seizure. To strengthen his muscles we practiced sitting and sit ups and standing, and arranged for the early intervention team to come, thanks to our neighbor who turned out to be a world's expert on cerebral palsy. He gave us the first words of hope since Zuleima's: "Don't go by the MRIs, go by his functioning. Neuroplasticity at this age is such that with his curiosity, sociability, and determination, he can become a CEO!"

We found a wonderful part-time Colombian nanny who spoke Spanish, hoping the boys would not lose the Spanish that was their first language for a year. But both boys initially had a great fear and aversion to Hispanic-looking women. Donald would cry upon seeing a dark-haired woman, and David became panic-stricken and screamed bloody murder. Being a child therapist, their reactions signified to me they had been traumatized by some form of abuse, probably in the second foster home. I noticed the first time we took them to the park that if our nanny took Donald to a different part of the park away from David (who could do so many things Donald could not), David became

almost paralyzed with fear, staring and pointing at Donald. I reassured him, ‘Donald will stay with us forever, she’s helping,’ but he never took his eyes off his brother. It would be months before David could feel reassured that he would not lose his “beebee” again. Our nanny was exceedingly gentle, and after a short time Donald relaxed with her, and after months David relaxed with her. Their traumatic reactions gradually faded as well.

The early intervention team and other therapists and doctors worked with us seven times a week. They agreed Donald suffered from hemiplegia (a form of cerebral palsy which means his left side was abnormally weak, with some muscles on the left side overly tight and causing contractures) and oral apraxia (failure of the mouth muscles to form speech, even though he knows what he wants to say). They also all said they had never seen such a determined baby.

In addition to times of progress, there were times of great trepidation. Waiting for an orthopedist to examine Donald for leg braces, I saw a tiny mother trying to carry her 14 year old son with cerebral palsy who was immobilized by casts on his legs. We learned from reading about cerebral palsy that surgeries to break and reform bones to correct joint malformation are annual experiences when the cerebral palsy is severe. At the park I saw another mother struggling to lift her 6 year old son with cerebral palsy out of the only swing he could use – which was made for infants. Another mother told us about her son whose cerebral palsy was so severe he could not swallow; his public school did not provide adequate supervision and during one school day he aspirated his food and died. We could not help but feel this could be us with Donald.

And then there was Donald, who struggled with great determination to do the next thing: first commando crawling, then crawling, then pulling up to cruise, then, at last a year later, walking. Every accomplishment was hard-won and each one initially seemed out of reach. Yet, in the end, it seems Zuleima was right.

A Future for International Adoption?

And what about international adoption and the orphans remaining in Guatemala (see Editors, New York Times, 2009 for a recent debate)? Even now, 700 Guatemalan orphans who were assigned to families in the U.S. are languishing in orphanages while federal governmental agencies delay adoption processing with often meaningless red tape under the rationale of investigating corruption (Aizenman 2009). Consider the possibility that Donald and David had not had the option of adoption. They would have lived in orphanages and access to medical care and nutrition would likely have been worse than what they received in Guatemalan foster care. Donald’s meningitis might well have led to his death; David’s rotavirus could have as well. If they had survived, Donald would have lived in a society lacking early intervention services and would have faced a future of being severely crippled and in pain. Assuming David had survived rotavirus, how would his twin brother’s plight have affected him? There is considerable documentation that Guatemalan orphans who survive live like the homeless 5 year old we saw in Guatemala City, selling CDs on the street, obviously the virtual slave of a “Fagin” type adult abusing him.

We now know that a normal brain development depends on family care in the years from birth to three. Is it not a violation of human rights to deprive children of the opportunity of family life by consigning children to orphanages where, if they survive, they can be permanently handicapped? It is remarkable that some opponents of

international adoption who discuss corruption in Guatemalan adoptions (e.g., Graff 2008) never include in their discussion the impact of state-sponsored genocide against Mayan families and children, and the often-fatal impact of profound poverty and inadequate orphanages and foster care on Mayan children. As Elizabeth Bartholet notes, those who oppose international adoption globally do so by documenting abuses that have occurred, but they lack evidence based on larger analysis of international adoption outcomes and also do not discuss the evils that occur on the other side: child abuse and neglect, malnutrition, disease, grossly inadequate orphanage care, etc. (Bartholet 2007).

Currently, international adoption of infants as one solution for infants and children in crisis (Roby & Shaw, 2006) has been significantly hampered because, in the name of human rights, some policy-makers (including UNICEF, see Bartholet, 2010) press for governmentally-enforced legal restrictions on international adoptions. The practical impact of those restrictions is ignoring orphans in need, leaving them homeless or dying on the streets, or consigning orphans to institutional care, indefinitely, as the adoptive process grinds on (Child Advocacy Program 2008). For an example, see the recent publicized situation of children whose orphanages were destroyed by the 2010 earthquake in Haiti. It was taking three years minimum for the government to process their adoptions (McKinley and Hamill 2010), by which time the most crucial period in an infant's brain development has elapsed and a child can be irrevocably injured (Perry 2002).

While corruption in international adoption is a most serious problem, corruption exists in many governments in the world, and rather than abolishing the institutions, customarily efforts are made to reduce and abolish corrupt practices. While that may be easier said than done, it is not impossible as some might claim. There are many ways to promote transparency in adoption, especially given DNA tests, photographs of birth parents and infants to verify identities, licensing standards and associations, and internet blogs where parents review the capabilities of lawyers and adoption agencies. The danger in relying only on public governments to carry out adoptions is exactly what has been learned by child welfare specialists in the United States (Bartholet, 2007): Public bureaucracy (and inadequate accountability) can be such that human services are generally carried out more effectively by private agencies whose work is reviewed and contracted by local, state, and federal government bodies.

Opponents of international adoption cling to a narrow concept of adoption as justifiable only when both parents are dead and all possible relative placements have been tried and exhausted, which can take years (see quotes from Save the Children staff in (Pidd 2009) and UNICEF personnel, McKinley & Hammill, 2010). By contrast, in the developed countries of the world, parents alone relinquish their children to be adopted if they believe they cannot adequately care for their children. In Illinois for example, birth parents have to wait 3 days after their baby is born before signing a relinquishment. Thus a double standard exists where adoption is a viable alternative for parents and children in crisis in developed countries, but not in the severely impoverished countries of the world, which actually lack the social service infrastructure to support poor families or provide adequate foster care and adoption services locally.

While the importance of a child growing up in her/his culture is often cited as a reason to oppose international adoption, aren't the opinions of birth parents worthy of respect? We were struck by the fact that in our domestic adoption, our daughter Naomi's

birth parents could choose who would adopt her. They said they wanted a family who would love and cherish her and give her siblings to play with and a fine education with opportunities to travel. They clearly felt those qualities were more important than whether the adoptive parents were of the same African-American race. Our twins' birth mother expressed similar beliefs. But Mayan parents who might want a child they cannot care for to grow up in a country where there is no recent history of genocide and terrorism against Mayan people, and where services for children and families are greatly improved over what exists now in Guatemala, cannot make that choice now.

Finally, while opponents of international and transracial adoption state that it is better for children to grow up in their country and community of origin, other child advocates argue that such a restriction is based on "extreme romanticism" rather than systematic study of international adoption outcomes and common sense (Bartholet, 2010; Child Advocacy Program 2008; see also Aronson's comments in Editors, New York Times, May 10, 2009). Moreover, in some countries a commitment to adopting children runs against custom or religious values, and while change certainly happens, it is not in time to save the lives of many orphans: In a prominent Sudanese orphanage that admits hundreds of orphans every year, conditions are so bad that a child dies every other day despite the best efforts of child welfare workers and UNICEF over several years to improve conditions (Polgreen 2008). If orphans reside in countries where their lives are threatened because of religious values, racism, gender bias, or extreme poverty, shouldn't they be able to reside in environments where they are safe and valued (Roby & Shaw, 2006)? While research has failed to document that transracial or international adoption endanger children's mental or physical health, it has demonstrated the dangers of the alternatives of homelessness, institutionalization, or inadequate foster care (Bartholet, 2010; Child Advocacy Program 2008).

Present

Reflecting on autoethnography

Writing this autoethnography has been cathartic and also an opportunity to reflect on the causes and potential solutions to the suffering inflicted on David and Donald and other orphans in crisis. While autoethnography's primary method is to delve into the very personal, I felt as a social worker it was important to give you, the reader, the benefit of additional literature about the central topics. Of course this particular autoethnography is also a work of advocacy, and it felt personally as well as scientifically important to document that there are other scholars whose arms are linked with mine in seeking to remove obstacles to international adoption and to improve care for homeless and orphaned children.

It seemed important also, given my research training, to consider whether in autoethnography one has to abandon all efforts to manage the challenges associated with intersubjectivity. Perhaps not. Since Bob was so involved with the process I asked him to review what I had written and make any changes he felt were needed to improve accuracy. There were only a few but they are all included in what you are reading, so this rendition has had an additional validation of its accuracy. Readers may also consider that the central facts have many witnesses: the twins' third foster mother, our translators, Dr. N., Zuleima, my brother-in-law's brother the pediatrician, etc.

I have been struck in writing this autoethnography that, just like in any research

project, what one chooses to focus on and then to leave out is of utmost importance (akin to Wimsatt's wonderful conceptualization of the environment-system boundary in scientific research, 1986). In the spirit of reflectiveness it is important to talk about my choices of what to include and what to leave out. As probably always occurs, one has to leave out much more than what one can include in one's focus: I talked little about my ongoing relationship with Bob, which would occur in a chronicle about a marriage; or about the hotel, Guatemalan Christmas traditions, the earthquake, what we ate and saw in Guatemala, which would occur in a tourist article; I spared the reader details of our advocacy for adopting the twins both before and after our visit to Guatemala, and also how we coped with the anger and sadness we felt at what was done to Donald and David. A chronicle focused on David alone would have recounted much joyful relating and funny times, such as my changing his poopy diaper for the first time while listening to the Bach cantata version of "A mighty fortress is our God." He became so excited he started rolling around the bed (with predictable results including laughing by all). We enjoyed his spunky antics and chuckled about our neophyte parenting ineptitude, but for space reasons could not include those moments in this account.

The straight track of the story I did tell here concerns the relationship between David and Donald, what happened to them as orphans, their near brush with being orphans indefinitely, their courage facing the diseases and loss they coped with, and finally their dedication to each other. So what I have left out was left out because it might detour from following the straight track of their story.

Finally, autoethnography embraces and builds on the subjectivity of the researcher's perspective, which has for years been scorned by positivistic social scientists as tainting the research process. In examining the connection between subjectivity and the knowledge-building process autoethnography makes an invaluable contribution to social science research. After all, subjectivity cannot be eliminated, and it is important to understand how it works and also to set a standard that helps researchers to reflect upon how their own subjectivity invariably influences their research. The experiences one has and the meaning one makes of them no doubt influence many aspects of one's work as a scientist, as was noted most famously by Thomas Kuhn (1962). For me the trauma and inspiration of the events chronicled here will no doubt influence my choice of research questions to pursue in the future, how I interpret the relatively sparse data that is available on the conditions of international orphans and outcomes of international adoption, and how I respond to scientific controversies that exist in the fields of global child welfare and care for children with special needs. For instance, the New York Times article that chronicled global child welfare agencies' efforts to reduce the massive death rate of children in a Sudanese orphanage was quite laudatory of the results the agencies received (they cut the death rate in half). However, it was striking to me that still, every other day, an orphan dies in that orphanage. All I had to do was picture our orphans as among those who die, and the data reported then reflect an ongoing and fundamentally preventable tragedy.

Consider also that the experiences a scientist has **not** had can color her/his research process. It became striking to me how many people comment on international adoption (policy-makers as well as researchers) without ever acknowledging potential sources of their own personal bias (for a notable exception, see Bartholet, 2010). It might affect one's research conclusions if one has never experienced a family united by

motivation rather than by sharing genes. Similarly, if one never had to give up a child for adoption or confer deeply with birth parents, it might be hard to adequately comprehend and respect birth parents and their wishes. Those who have not personally experienced the terrible suffering of orphans sickened, starving, and dying may find it easier to take an exclusively muckraking focus on corruption in international adoption and to ignore the urgent needs of orphans and the many happy and productive families created through international adoption.

A researcher's passionate interests can be powerful incentives to think and investigate deeply and thoroughly, so perhaps subjectivity only compromises the quality of scientific research when its impact is ignored and researchers, assuming they can be purely objective, ignore important realities.

Before ending this autoethnography, readers may want to know more about how the parent dream is coming to earth in the present...

Parent dream as it is happening now

When David and Donald were 2 and a half, we had the joy of being able to adopt a beautiful baby daughter, Naomi (through a domestic adoption). David and Donald are excited about her, help feed her her bottle, offer her their trains to play with, and pat her lovingly. Space does not allow a focus on the gift of parenting Naomi, but readers may understand the wonder of being able to help a brand new person experience so much of life for the first time: first bird songs, first summer sunlight streaming through trees, first waves on the lake and ocean, and most of all, getting to know the wonderful person she is. Caring for Naomi in her first months of life I realized the terrible vulnerability of our sons, how frightening it was to be with foster mothers who did not give them the care they needed and to feel all their surroundings were so unpredictable. The tragedy of infants who don't even have foster mothers but instead are neglected in orphanages has an even more profound meaning now. When we took Naomi to get her vaccines, I saw her receive not just once but several times vaccines for rotavirus and pneumococcus....each time I thought about our sons and what other poverty-stricken children do not get; how simple the vaccines are to give and how grave the illnesses are when the babies do not receive them.

And here, now, at this writing in the winter of 2009, it is almost exactly two years since we first met our wonderful sons in Guatemala, David in the hotel, and Donald in the hospital. Outside a blizzard is howling as it did when we got the news that one of our sons was ill, and while we were packing to go to Guatemala. That time is most alive inside me and may always be as the snows of winter blanket Chicago and represent to me what seemed to be a numbing blanket of corruption and brutal inhumanity in the seemingly snow-free Guatemala. Orphans and poor children in Guatemala are starving for food, medical care, and love, we know. The adoptive parents to whom Guatemalan children were assigned are in anguish while the current bureaucracy goes around in circular investigations of investigations of adoptions 'in process,' with no hope of recourse (see Aizenman, 2009).

In our home, we are recipients of what Dr. N. said could only be a miracle. Now three, our boys are rambunctious, and ready to go at life with all their gusto and infant integrity. Donald hasn't had a seizure since his illness and no longer takes the medication that made him so spacey. With new hinges on his leg braces, Donald can run. He can reach out and hug with his left arm, and although he can't speak words yet, he

communicates in all kinds of ways that his understanding of English and Spanish is nuanced and at a three-old's level of sophistication. He is incredibly social and active, dancing in his own way along with David; hugging everyone he meets; his eyes full of sparkle and laughter as he makes jokes for himself, David and Naomi that are best understood only by babies. He chortles with glee when tickled and sharing jokes with us. He feeds himself steadily and with great concentration and there is no food he refuses. He reads books avidly and he adores his trains and trucks and is completely fearless about going on rides at amusement parks and zoos.

There are other kinds of miracles too. David and Donald hear each other in ways we can't fathom. Donald fell a few months ago and when he was still limping the next day I told the boys I was going to take Donald to the doctor, maybe he hurt his ankle. David said, "his toe." I said "Oh, which toe?" David pointed. We took Donald to the doctor, and sure enough, the little toe David identified had been slightly fractured in the fall and everything else was fine. Donald can't talk, so how did David know? Last night Donald sat down and David said, "Donald want braces off." I said to Donald, "Do you want your braces off?" Donald said, "Yeah!" and David said, "let me." He carefully took off Donald's shoes, then the several latches on his braces, then his braces, then his socks, and inspected Donald's feet. "That red" he said, and I said, "yes the braces are new, they can hurt while he's getting used to them it's so great you let us know they started to hurt and helped take them off."

While we were going through our journey to parenthood, there was so much to do I could not think much about what I was experiencing. Now I think about my parent dream, where I started, and I realize how as that dream came to earth it was so much richer and also so much more fearsome than I could have imagined. For all of us, every time we love anew we can be faced with terrible loss and have to overcome our fear of loss in order to love. Sometimes the loss of the person we love stares us in the face as it did with Donald; sometimes it is more lurking and flares up, as in David's bout with rotavirus; sometimes we know it is inevitable, like old married partners who talk about who will die first and who will be left with the grief.... It is so terribly difficult to let ourselves love in the face of the chasms of loss and attendant pain that open up in each relationship. And yet an essential part of our humanness is denied if we run away from the loss and try to stop love; and no other fulfillment of our human nature can possibly equal what happens when we embrace our love of another and let ourselves fall into it completely as it should be.

The future for David and Donald is full of challenges. David and Donald will learn of the injustices done to them, and also will know about the many people who helped them with the impact of those injustices. Donald will need multiple therapies for years and special schools, and just as importantly, help knowing his strength and value, given how he was horribly injured. He will need Botox treatments to have even a hope of being able to use his left hand, and he is struggling to make his mouth muscles form even the smallest words. Yes! he says with great gusto, raising his right hand in the victory sign. And No! he can say with great determination. But other words come out only as vowels, oooo for juice. And he gets terribly frustrated, so much to say and his muscles won't work to say it. The part of his brain that was the most damaged was Broca's area and his brain will need to make new connections to enable his speech. He tries enormously hard and we try to do him justice.

This morning when I came in to their bedroom, I saw David saying to Donald, “Want help getting down?” (out of bed). Donald said, “yeah” and scooted towards the end, where David then took him by his night braces and his feet and pulled while Donald pushed. Donald started sliding down and David put his arms around his waist to stabilize him, saying, “Okay, Donaldy?”

Tonight, David and Donald, getting ready for bed, are playing at their train table. In the delicate language of a three-year old trying out his words for the first time, David makes up a story of how Thomas the train runs into a pig on the track. What will he do? They talk to the pig and the pig decides to get off the track so they can go further. But then Thomas and the trains he is pulling hit another obstacle and need the hero, Harold the Helicopter, to save them. In their world, Harold comes and can save them. Problems solved, pig and trains and heroes intact. We put on Donald’s night braces. Going to bed, they invariably sleep snuggled close. “Ever and ever” says David, as he goes to sleep, his refrain that means we will love them both, and be a family together, forever and ever. Donald pops up to check on David, and, reassured, makes a snoring sign to indicate David is sleeping and he will too, and lies back down. Donald’s right arm reaches out to hold my hand, and his left arm that was paralyzed reaches out to hug and hold onto David as he falls asleep, and with these gestures he speaks volumes.

Epilogue

As this book goes to press, there is an opportunity to look at some elements of our story from a present vantage point. First, now Donald can speak several syllables at a time, he runs, he shouts, he sings, and he is still laughing. He is in a great special education preschool and has therapies four times a week, made affordable thanks to Obama’s health care legislation. He plays continually and avidly with David and Naomi. While many aspects of Donald’s future abilities remain highly uncertain and can be a cause for great worry, at the same time he makes steady headway, so we have grounds for much hope. While I was writing this, Donald ran in from going on an errand with Bob, said, “your lap” and climbed on my lap. While eating a chocolate cupcake and doing a train game together on the computer, he periodically reached up and pulled my face down to kiss with a chocolate kiss and a big smile.

From a 2012 vantage point, information is available about what would likely have happened if we had not been able to adopt David and Donald in early 2008. As was noted previously, the Guatemalan law that was passed in December 2007 that mandated establishing new oversight processes, as well as new government structures for international adoption, brought international adoption to a screeching halt. As of 2012, there still are 900 Guatemalan children who have families ready to adopt them internationally, but whose cases are stalemated in the bureaucracy. The children are growing up in transitional situations including institutions (Guatemala 900).

Many commentators remark the new law resulted in no substantive improvements for orphans in Guatemala. In fact, one orphanage director, who says her orphanage is privately funded because the public funding red tape is convoluted and corrupt, comments that the government made a terrible mistake ending international adoption. Now, she says, the government has to pay for all the orphans and does not allocate the resources. Previously, the fees paid by adoptive parents funded a considerable child welfare infrastructure of foster parents, medical care, social services, and legal oversight

for child welfare processes (Reason, 2012). Meanwhile, the numbers of Guatemalan street children and orphans in dreadful conditions are growing exponentially -- one of the babies growing up in the director's orphanage was found abandoned in a garbage can, with dogs starting to eat her (Reason, 2012). Guatemalan children are victimized through forced labor (such as forced begging and working in garbage dumps), trafficking in Guatemala and via kidnapping to other countries, and child sex tourism (U.S. State Department, 2012). One of the leading humanitarian organizations protecting Central American street children estimates over 15,000 Guatemalan girls are victims of brutal sex trafficking (Casa Alianza, 2012). In 2010 a student in my global social work class volunteered on several occasions helping street children in Guatemala. She described and showed pictures about how police in Guatemala City routinely doused sleeping street children with gasoline and set them on fire. The existence of such conditions makes it impossible to reasonably claim that international adoption should be halted in order to preserve "cultural values." Indeed, policies that preserve values of child homicide and genocide appear to be, as James Garbarino writes (2008), the "dark side of human experience."

Elizabeth Bartholet comments that international adoption was "a remarkably effective social program," in that it provided immediate and enduring life-saving help to thousands of orphans every year, using private rather than public funds (2010 and in Reason, 2012). Some hope that with enough public awareness, the tide may turn again in favor of supporting international adoption (www.bothendsburning.org).

It seems to me as I write this that perhaps a major motive behind autoethnography is the hope that by telling one's story and listening to each other, we can make a better world based on the truths we learn. So thank you to you, the reader, for reading and listening.

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